

Holding Space: Family-centered informed choice

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Disclosure

- ✓ Andrea Amestoy, R.N., Erika Blanchard, CCC-A, or Brian Shakespeare, EHDI Coordinator have no financial or conflicts of interest to disclose in relation to this presentation.

Objectives

- ✓ Learn strategies for empowering families to make informed choices about intervention options.
- ✓ Understand how to break down benefits, risks, and uncertainties related to various intervention options.
- ✓ Learn the concept of Holding Space for a family as they make decisions that are right for them.

Definitions

- ✓ Family Centered Care: Patient- and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families.
- ✓ Empowerment: Giving families a sense of control over themselves, their child, and their family.
- ✓ Holding Space: To walk alongside another person in whatever journey they are on without judging them, making them feel inadequate, trying to fix them, or trying to impact the outcome.

Definitions

- ✓ Early Intervention: A system of services that help children with developmental delays or disabilities to learn the basic skills that typically develop during the first 3 years of life.
- ✓ D/HOH: Deaf and/or Hard of Hearing
- ✓ Deaf: Culturally Deaf individuals self-identify as a primary user of American Sign Language (ASL).
- ✓ deaf: Individuals with Severe to Profound hearing loss that self-identify as a primary user of spoken or visual language (Audiologically deaf).

Idaho survey data

- ✓ 103 Intervention Professionals surveyed
 - ✓ How often do you counsel families of children that are D/HOH
 - ✓ Very often or Somewhat often = 29 of 66 respondents
 - ✓ How comfortable are you in counseling families of children that are D/HOH = 46 respondents
 - ✓ Very comfortable = 5 respondents
 - ✓ Somewhat comfortable = 19 respondents
 - ✓ Not very comfortable = 16
 - ✓ Never performed this task = 6

Family Centered Care in EI for children D/HOH- International Consensus Statement

✓ Principle 3: Informed Choice and Decision Making

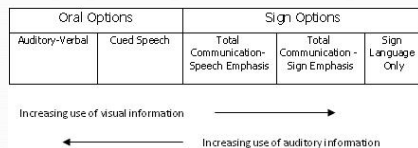
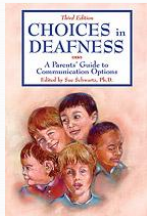
"Informed choice is not synonymous with information that is neutral or functionally descriptive. Rather evaluative information is essential in that it draws attention to the various risks, benefits, and uncertainties related to that particular option."

Family Centered Care in EI for children D/HOH- International Consensus Statement

✓ Decision Making with Families

- ✓ Families need facts, not opinions, to make the right decision for their children and families.
- ✓ Families need to feel okay with making a different decision that you would
- ✓ Fear of being judged will hinder the family from making a decision
- ✓ The decision is the families, not the professionals
- ✓ We are just "holding space"

Un-Biased Communication Options: Take your pick



BAR: decision making in times of trauma- A lesson from nursing

- ✓ B: Benefits -What are the benefits or the pros of this treatment option? How will this help my baby/child?
- ✓ A: Alternatives -What other alternatives exist? What other options are out there?
- ✓ R: Risk -What are the risks or the cons of this treatment option? How might this negatively affect my baby/child?

BRU: Family centered Decision making and informed choice in communication option

- ✓ B: Benefits -What are the benefits or the pros of this communication modality? How will this help my baby/family?
- ✓ R: Risks -What are the risks or the cons of this communication modality? How might this negatively affect my baby/family?
- ✓ U: Unknown/Uncertainties – What don't we know about the outcomes of this communication modality?

Informed Choice: Communication Options

	Auditory-Oral Options		Manual-Visual Options		
	Listening and Spoken Language (LSL)	Cued Speech	Total Communication -Speech Emphasis	Total Communication -Sign Emphasis	Sign Language Only
Benefits	Most people use spoken language to communicate	Relatively simple for families to learn	Allows for cultural access to both communities	Allows for cultural access to both communities	Allows early access to language
Risks	Dependence on assistive technology and audibility	Not widely used in Idaho	Reduction in focus on visual comm., reducing fluency	Reduction in focus on verbal comm., reducing fluency	Reduced access to communication with the general population
Uncertainties	How will the child identify culturally?	Unknown access to support services	How will the child identify culturally?	How will the child identify culturally?	What will the impact be on literacy skills?

Holding Space

-Heather Plett www.heatherplett.com

- ✓ Offering gentle, non-judgemental support and guidance



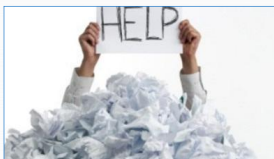
1. Give people the permission to trust their own intuition and wisdom

- ✓ Allow families to follow the path that will work best for them and their family.



2. Give people only as much information as they can handle.

- ✓ Do not overwhelm families vast amounts of information.



3. Don't take their power away

- ✓ Taking decision making power out of people's hands leaves them feeling useless and incompetent.



4. Keep your own ego out of it.

- ✓ It is not about you!



5. Make them feel safe enough to fail.

- ✓ When people are learning, growing, or going through grief or transition, they are bound to make mistakes.
- ✓ Withholding judgment leaves them the space to find the courage to keep going even when they fail.
- ✓ Failure is a part of the journey, not the end of the world.



6. Give guidance and help with humility and thoughtfulness.

- ✓ Know when to withhold guidance and when to offer it gently.
- ✓ Recognizing when people feel vulnerable and incapable and offering the right kind of help without shaming takes practice and humility.



7. Create a container for complex emotions, fear, trauma, etc.

- ✓ Create a space where they feel safe enough to allow complex emotions to surface.
- ✓ Offer strength and courage.



8. Allow them to make different decisions and to have different experiences than you would.

- ✓ Respect people's differences.
- ✓ Recognize those differences may lead to them making different choices than you would make.



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